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AUTHOR Gallagher, James J.; And Others
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ABSTRACT

This report was prepared as part of a 5-year study of the states' implementation of federal legislation regarding infants and toddlers (the Education of the Handicapped Act, Amendments 1986). In spring of 1988, a survey was made of key state personnel to assess current implementation status along a number of critical dimensions: definition and eligibility criteria, finance, family plans, interagency service coordination, and data systems. The survey found that 25 states had definitions for "developmentally delayed," while 20 states were considering or revising their definitions. From 4 to 15 different financial sources were being used to support programs for infants and toddlers; 14 states reported no coordination of funds, while 28 states reported efforts to coordinate sources. Nineteen states were using a former or existing interagency planning group to serve as the Interagency Coordinating Council, while 24 states formed new councils. Only five states reported having an Individual Family Service Plan (IFSP) meeting the requirements of the law, while 18 states were developing IFSP formats and 16 states were developing IFSP guidelines and policies. Forty-four states indicated that they had data available for at least one of the four required annual report categories. (Author/JDD)

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A SURVEY OF CURRENT STATUS ON
IMPLEMENTATION OF INFANTS AND
TODDLERS LEGISLATION
(P.L. 99-457, PART H)

JAMES J. GALLAGHER
GLORIA HARBIN
DAPHNE THOMAS
MARTA WENGER
RICHARD CLIFFORD

APRIL, 1988

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EXECUTIVE SUMMARY

The passage of PL 99-457 The Education of the Handicapped Amendments of 1986 was a significant move forward in calling for comprehensive and coordinated services to infants and toddlers with handicapping conditions. The Carolina Policy Studies Program has been awarded a contract by OSEP to carry out a five year policy study of the implementation of this legislation. This report provides some present status information on the states' efforts to implement the law.

The survey asked key state personnel in charge of Part H where their state was with regard to several key implementation dimensions and found the following from the fifty states and District of Columbia.

- Eligibility. Twenty five states report that they have a definition for developmentally delayed. Twenty states are considering or actively revising their current definitions.
- Finances. States report that from four to 15 different financial sources are currently being used to support programs for infants and toddlers. Fourteen states report no coordination of funds, while 28 states report efforts to coordinate sources, with an average of five sources being coordinated in those states. Funds most likely to be coordinated were private insurance, medicaid, and state health funds.
- Interagency Coordination. The Interagency Coordinating Council established in this law is drawing substantially upon past experience in the states. Nineteen states are using a former or existing interagency planning group, while twenty four states have a new council which has members from former interagency groups.
- Individual Family Service Plan(IFSP). This new requirement found states slow in moving on policy guidelines for the state level. Five states reported having an IFSP that meets the requirements of the law, eighteen states are developing IFSP formats, and sixteen states are developing IFSP guidelines/policies.
- Data Systems. Thirty seven states indicated that they had some data available on children served, twenty

eight had data on children served by type of services, twenty seven states had data on the professionals providing service and nineteen states on the amount of funds expended on early intervention services.

- A final word. There is substantial evidence that states are making a good effort to carry out this legislation. States that already had entitlements appeared to be ahead, except for the development of IFSP policies. The range of tasks required for implementation of the law makes it likely that the four years allowed for states to become operational may hardly be enough, in some instances, unless substantial additional resources are made available from some source or sources.

The passage of P.L. 99-457, The Education of the Handicapped Amendments of 1986, was a significant move forward in the thirty year federal effort to bring help and support to handicapped children and their families. For the first time, in Part H of that law, it calls for a comprehensive and coordinated effort across agencies and professional disciplines to deliver services for children under three with handicapping conditions, or to children who would be at risk for such conditions.

This law closes the final circle of federal legislative initiative designed to see to it that all children with handicaps receive appropriate services as early as needed. At the same time, the implementation of Part H (Infants and Toddlers) of the Education of the Handicapped Act Amendments of 1986 is one of the most challenging tasks yet confronted by the various professions and agencies involved.

This law challenges us to develop a system of multidisciplinary coordinated services, to involve parents in the planning and treatment programs, to design complex financial systems of payment in a timely fashion, etc. All of these requirements mean that implementation of this law will not be easy or instantaneous and the law recognizes that by giving the states four years to become fully operational.

The Carolina Policy Studies Program (CPSP) has received support from the Office of Special Education Programs in the U.S. Department of Education to carry out a five year policy study of the implementation of the law. One of the first tasks of CPSP is to provide some statement of current status of the states along a

number of critical implementation dimensions: definition and eligibility criteria, finance, family plans, interagency service coordination and data systems. This short report is an initial statement of where the states stand in these dimensions as of Spring of 1988.

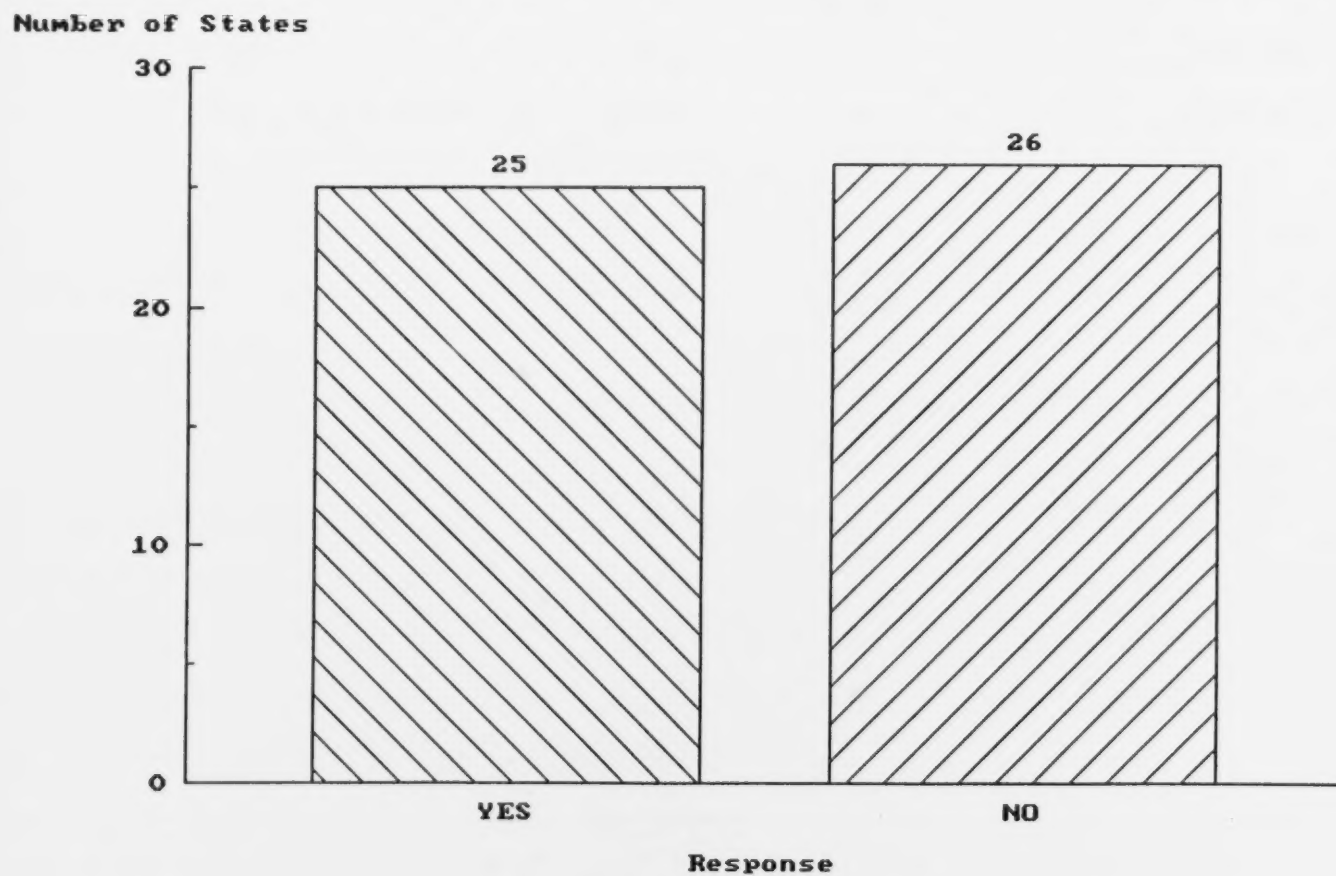
This information was collected by CPSP from the persons responsible for the Part H programs in their states during meetings which focused on their needs for technical assistance conducted by the National Early Childhood Technical Assistance System (NECTAS).

ELIGIBILITY

P.L. 99-457 requires each state to develop a definition for developmentally delayed as a step towards determining who is eligible for services under the law. Development of this definition, with accompanying eligibility criteria, is a major policy issue and challenge for most states. Decisions concerning who will be eligible are likely to raise significant issues in many states and are of special interest to the Carolina Policy Studies Program. That survey revealed three interesting findings in this crucial policy development area.

First, there were 25 states who indicated that they currently had a definition for "developmentally delayed." Figure 1 presents the number of states with and without a definition for developmental delay as reported by the Part H representatives. Interestingly, four states with entitlements for serving birth-to-three year olds, utilizing the P.L. 94-142, The Education for all Handicapped Children Act, definitions and

Figure 1. Number of States with a Current
Definition for Developmentally Delayed
n = 51



categories, reported that they did not have a definition for developmentally delayed, although they are providing services. Some states had been serving infants and toddlers with handicaps prior to the passage of P.L. 99-457. In these instances some states based their definition on the federal Developmental Disabilities definition, others based theirs upon the definitions in P.L. 94-142, and others developed theirs from a variety of sources. Since the passage of P.L. 99-457, some states have developed a definition which corresponds to the parameters of this legislation. Therefore, as of January, 1988 the definition and eligibility criteria concerning the "developmentally delayed" infant and toddler varied greatly among the 25 states who reported having a definition.

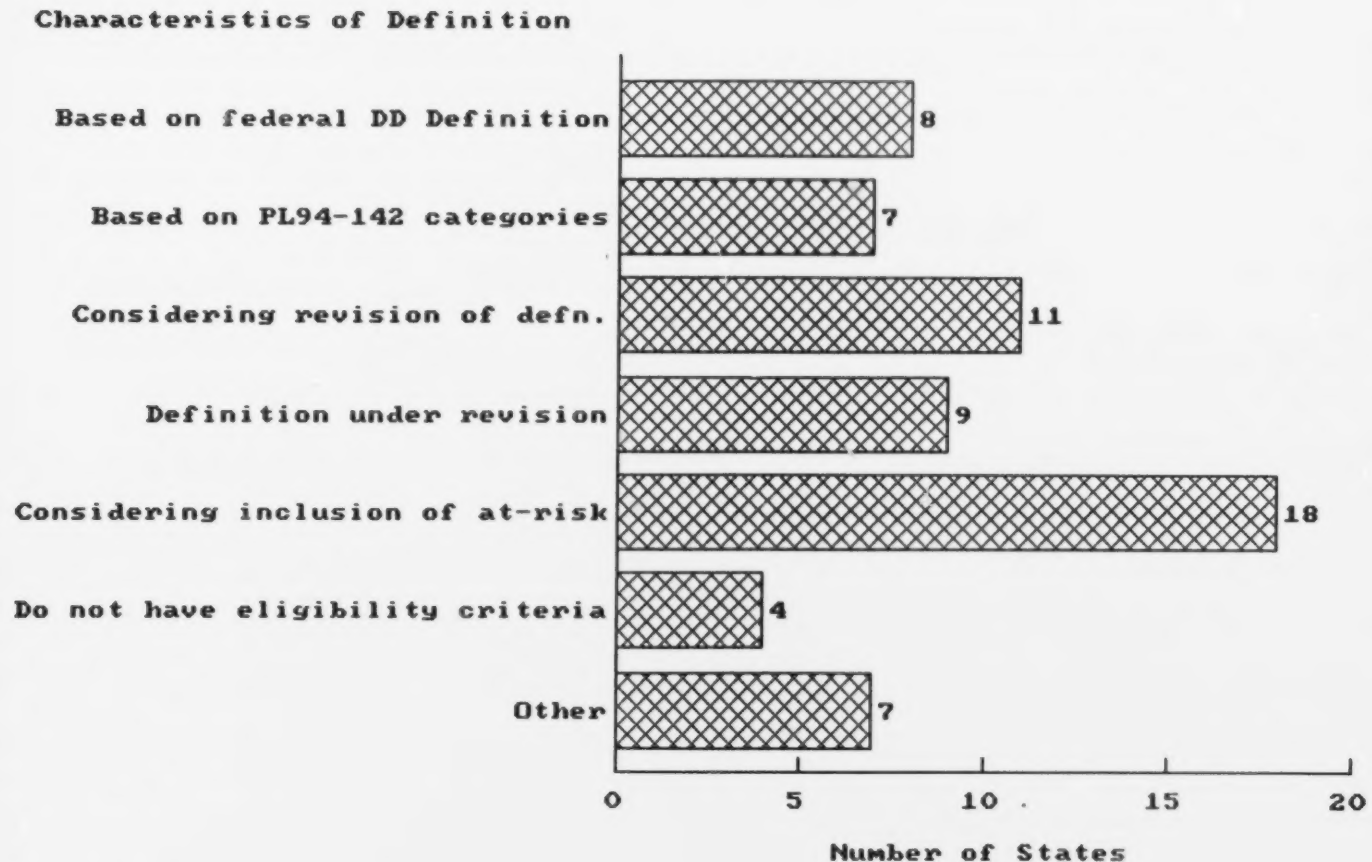
Many individuals are interested in whether states who currently have a definition come primarily from a particular lead agency. An examination of the lead agency for those 22 states with definitions reveals that: (1) nine come under Health in some way (e.g., Dept. of Health, Health and Environment, Health and Social Services, etc.); (2) six come under Education; (3) four come under a large umbrella Human Services or Resources agency; (4) two have an interagency or interdepartmental council as the lead agency; (5) one is under Developmental Disabilities; (6) one is in Mental Health; (7) one is in the Department of Developmental Services; and (8) one is in the Governor's Office for Children and Youth. Therefore, of the states with a current definition, most are either in the Department of Health or Education.

The second finding of interest concerned states' satisfaction with their current definition. Figure 2 indicates that of the 50 states plus the District of Columbia, 11 reported considering revising their current definition, while 9 more reported that the current definition was under revision. Thus, 20 states are not completely satisfied with their current definition for serving infants and toddlers with handicaps. Consequently, there are likely to be changes in many of these current definitions over the next year.

The third interesting finding relates to the inclusion of the "at-risk" population. Of the 50 states plus the District of Columbia responding to the survey, 18 indicated they were considering the inclusion of infants and toddlers at risk as part of the definition. Respondents were not queried about which types of "at-risk" children they were considering. Therefore, it remains to be seen whether any of these states will include both the biologically (medically) and environmentally at risk, or some subset of either group.

Many individuals are concerned that the type of lead agency (e.g., Health, Education, etc.) might influence whether the state will be interested in considering the inclusion of "at-risk" children within this program. An examination of the lead agency for those 18 states considering the inclusion of "at-risk" reveals: (1) seven are under Education; (2) six are under Health in some way (e.g., Health, Health and Social Services, etc); (3) five states are under five different agencies (Social Services, Mental Health, Developmental Disabilities, Human

Figure 2. Characteristics of States'
Definition of Developmentally Delayed
n = 51



Resources, Mental Health/Mental Retardation). In the area of eligibility, there is a wide diversity in the states in their progress to achieving a satisfactory definition of developmental delay.

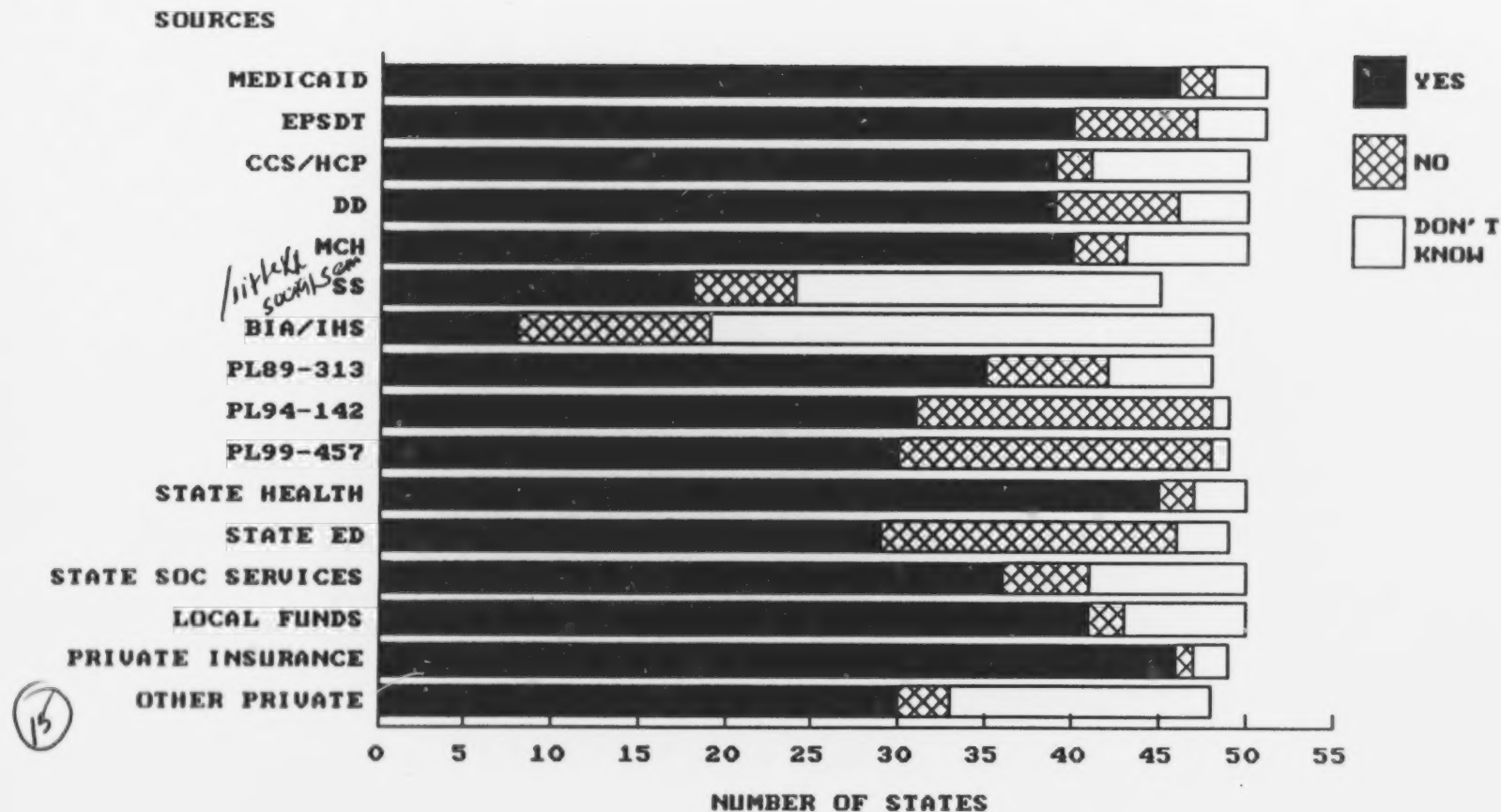
FINANCE

In order to obtain preliminary information on efforts by states to use a wide variety of resources to finance services for infants and toddlers with handicaps and their families, we have asked two major questions in the survey: (1) What sources of funding are used in your state and (2) What funding sources are being coordinated. It should be remembered that in each case we asked these questions of the lead agency representative -- not of the person responsible for each of these funds at the state level.

That fact does not diminish the importance of the information. If the lead agency person does not know that a given source of funds is being used (e.g., Social Services Block Grant), we take that to mean that there is no systematic effort to use that source for services to this population of children and families. Similarly, if the lead agency person does not know that sources of funds are being coordinated, we have taken that to mean that systematic coordination is not occurring.

Use of Funding Sources. Figure 3 provides a summary of responses by type of funding source. All of the fifty states and the District of Columbia were using multiple sources, from four to fifteen different sources with an average of just over eleven sources per state. The average number of sources used was not

Figure 3: Numbers of Funding Sources
Used by States
n = 51



Note: Some states did not respond regarding certain funding sources.

influenced by the type of lead agency (Education, Health, Human Resources, Interagency, Other) or pre-existing state entitlements guaranteeing services to all handicapped children. The most frequently used sources were Private Insurance (94%), Medicaid (90%), and state health funds (90%). Those sources of support least frequently used were PL 94-142, PL 99-457, and state education funds that were not being used for infants and toddlers with handicaps. We had also asked state representatives to indicate if they were unsure about whether or not funding sources were being used. The funding sources about which the lead agency personnel were the most unsure were the Bureau of Indian Affairs/Indian Health Service Funds (60% did not know), Social Services Block Grant (SSBG) (47%), and other private funds (31%).

Since the BIA/IHS funds apply only in states with designated native American groups, the responses to use of these funds should not be compared directly with other sources. In fact, of the twenty-seven states eligible for BIA/IHS funds, eight were actually reporting use.

Health-oriented funding sources appeared to be used more frequently than other sources, regardless of whether they were federal, state, or local/private. Education funds which have traditionally been targeted toward older children are used less frequently but, even then, by over half the states. Finally, it is surprising that the Social Services Block Grant was used by only 40% and was an unknown for nearly half the states (47%)! Since the SSBG is used widely for child care service for low

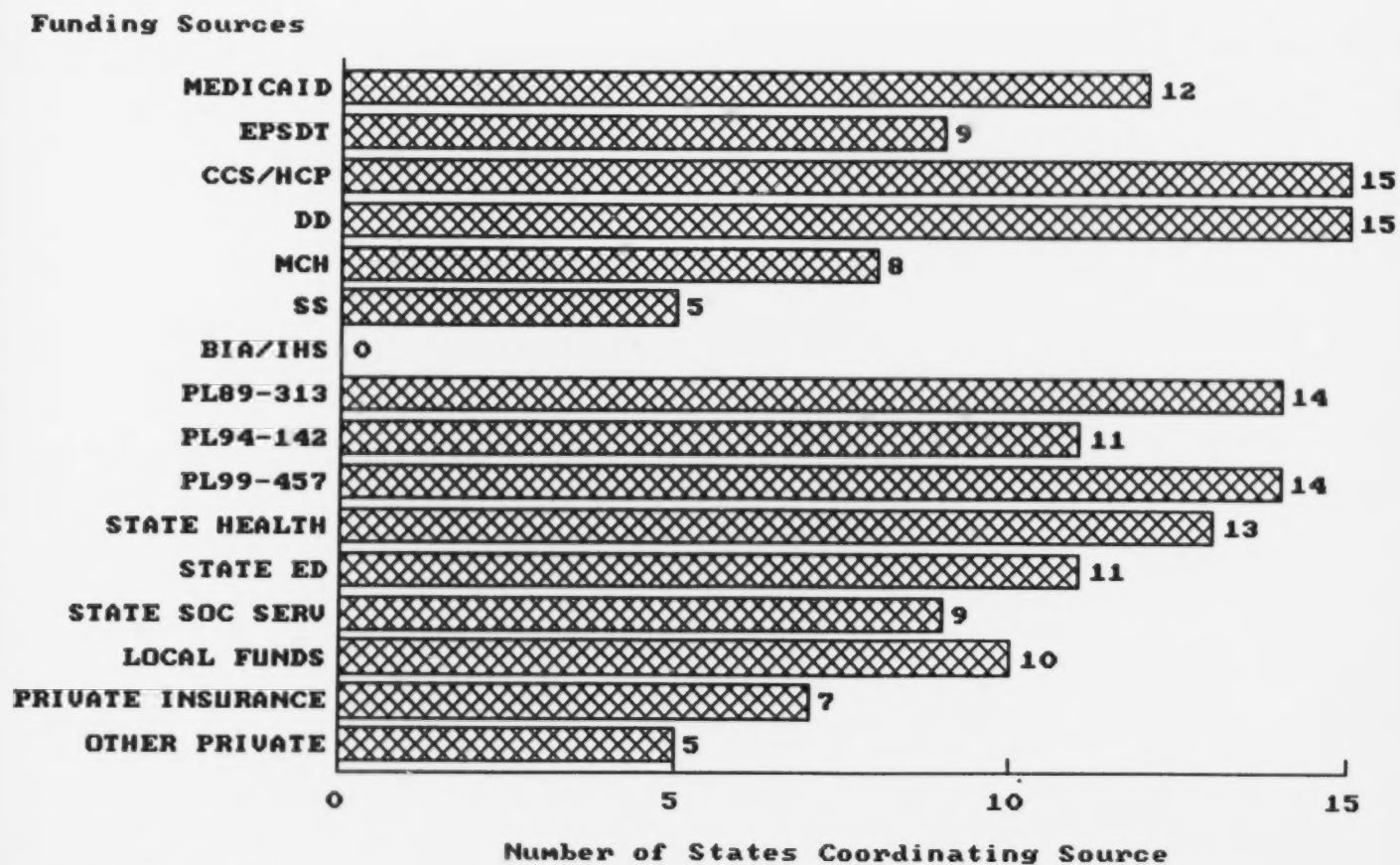
income, at-risk and developmentally delayed children, this finding was particularly significant.

Coordination of Funds. While states used on average some eleven different sources of funds, many fewer were being coordinated. In fact, fourteen states indicated that no coordination currently exists. Two did not know about coordination, leaving thirty-two (67%) indicating some effort to coordinate use of these funds. The type of lead agency and pre-existing entitlements to handicapped children did not have an effect on the extent of coordination of funds. Twenty-nine states indicated the specific sources which were being coordinated. States ranged from two to fifteen sources coordinated with an average of over five sources being coordinated. Most states reported restricted coordination to three or four sources of funds (fourteen states).

Figure 4 depicts the frequency of state efforts to coordinate funds by source. It is important to note that no specific definition of coordination was imposed on lead agency personnel responding to the survey. The comments on the forms indicated a wide range coordination efforts, ranging from informal efforts by staff members, to formal written interagency agreements.

Sources most often listed as being coordinated include Crippled Childrens' Services (15 states) and Developmental Disabilities (15 states), with PL 99-457 (14 states), PL 89-313 (14 states), state health funds (13 states), and medicaid (12

**Figure 4: Coordination of Funding Sources
by State
n = 29**



states) close behind. No source of funds was being coordinated by as many as a third of the states in the survey.

As one would expect at this stage in the implementation of PL 99-457, state agency personnel have made a good beginning at identifying the wide range of funding sources available for providing services for infants and toddlers with handicaps and their families, but have made relatively little progress at actual coordination of use of these resources.

It will be most interesting to see if significant progress can be made in the next few years in the difficult task of coordinating the broad range of fiscal resources, each bound in its own bureaucratic environment. It is encouraging to see that state personnel are making limited headway in this effort early in the second year of implementation of the law.

Interagency Coordination

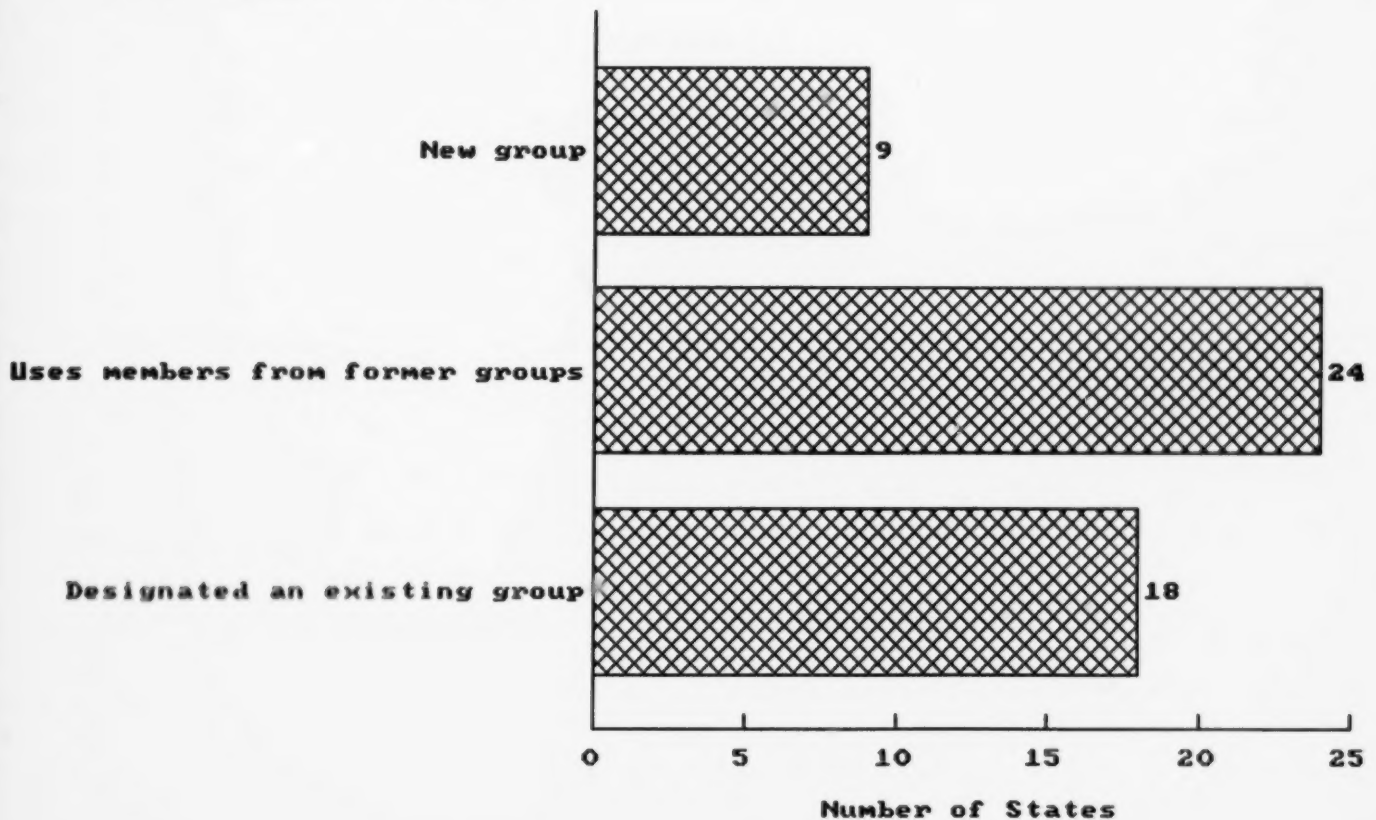
P.L. 99-457 directs the Governor to appoint an Interagency Advisory Council which will advise and assist the lead agency in the development of comprehensive, multidisciplinary, coordinated, interagency services for young children with handicaps from birth to age three. The legislation, P.L. 99-457, spells out the composition of this council, the functions and frequency of meetings, as well. Prior to this legislation, most states had formed some type of interagency advisory council, which was connected to one or more federal initiatives going on within the state. These included: State Plan Grant (funded by OSEP under P.L. 98-199), National Center for Clinical Infant Program's 0-3 states (funded by Maternal and Child Health), Georgetown

University's Networking project (also funded by Maternal and Child Health), and the state Developmental Disability Councils. P.L. 99-457 indicated that an existing council could be utilized providing it was comparable to the council specifications in the law.

Survey respondents were asked to indicate whether (1) a former or existing interagency planning group had been designated as the ICC; (2) the Interagency Coordinating Council is new but used members from former interagency planning groups; or (3) the Interagency Coordinating Council is an entirely new group. When P.L. 99-457 was passed and gave the Governor the responsibility of selecting the ICC, many states feared that the work done and the foundation laid in these aforementioned programs might be overlooked, ignored or undone. Survey results, as seen in Figure 5, indicate that most states will be including representatives of past interagency planning efforts. There were only nine states that indicated that the state Interagency Coordinating Council was a new group. Eighteen states are using a former, or currently existing, interagency planning group. While twenty-four states have a new council which has members from former interagency planning groups. In most states there is an effort to build upon previous efforts to further interagency coordination. Some states indicated that they would be using local interagency councils with a similar function to the State Councils.

**Figure 5: Characteristics of States'
Interagency Coordinating Councils**
n = 51

Characteristics of the ICC



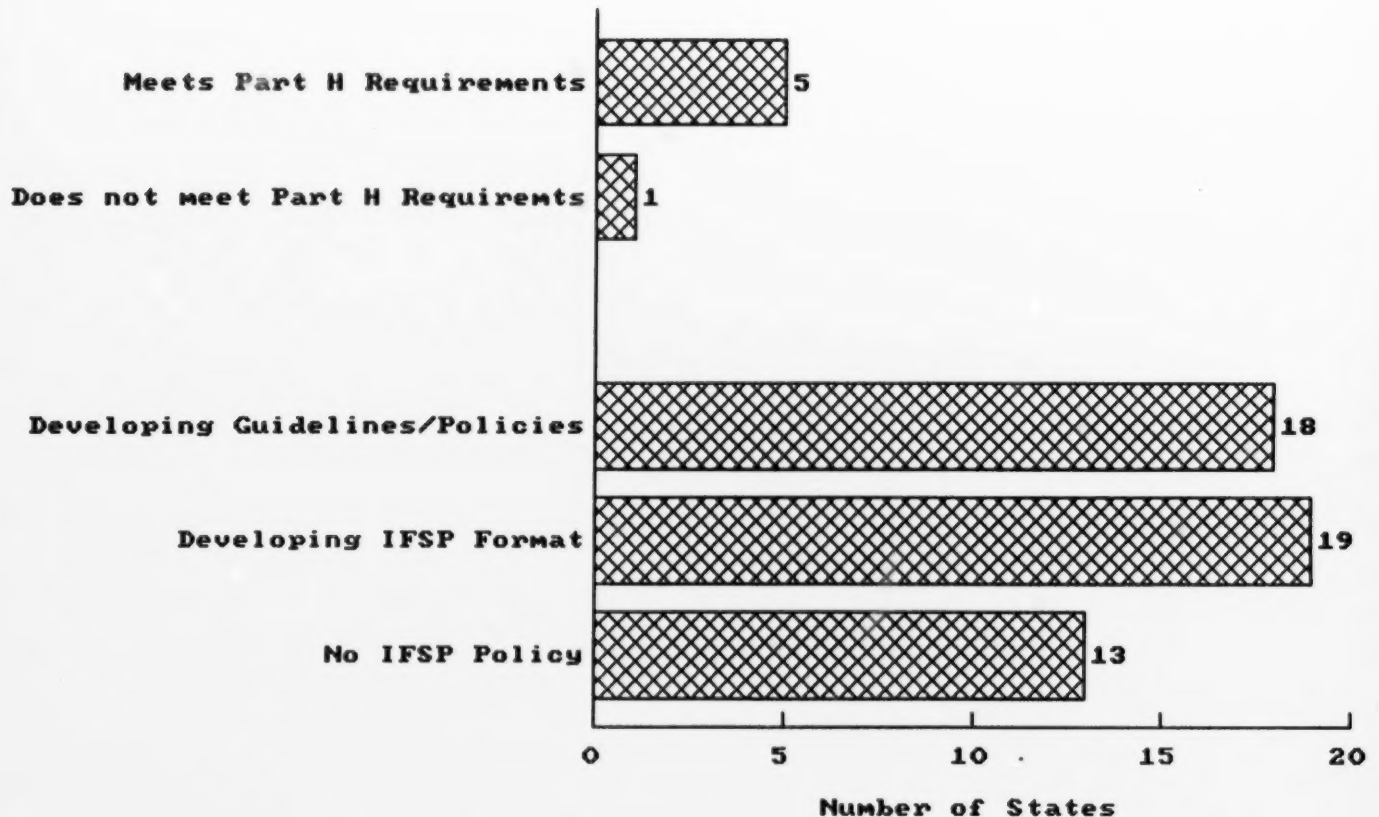
Individual Family Service Plan

The new requirement for an Individual Family Service Plan presents states with a different sort of a challenge since this was previously not an expected part of most early intervention programs. Five states (11%) reported that they are now using an IFSP that meets the requirements of P.L. 99-457. One state reported that they have been using an IFSP, but it does not meet the requirements of P.L. 99-457. Of these five states, one state is piloting the IFSP with neonates only, another is using a combination of the Individual Family Service Plan and the Individual Intervention Plan to gather family information. Nineteen states (38%) are developing IFSP formats and eighteen (36.0%) are developing IFSP guidelines/policies.

Thirteen of the states surveyed (26%) indicated that they have no policies concerning the use of an individualized plan for infants and toddlers (Figure 6). Of the thirteen states with no policy concerning IFSP's, six are developing formats, and five are developing guidelines and policies. It is interesting to note that some states are developing formats before they have policies. The pressure to provide practical guidance on the IFSP procedures apparently is overriding the development of an overall guiding policy. Five states reported that they have no policy concerning the regulations for the use of an Individualized Family Service Plan and have no current plans for developing formats, guidelines, or policies in this area.

Of the eighteen states with education designated as the lead agency, one state is using an IFSP that meets the requirements of

**Figure 6. Characteristics of
Individual Family Service Plans
n = 51**



**Note: One state did not report guidelines,
format, or policy data.**

P.L. 99-457. Eight states with education as lead agency states have established no policies in this area, and nine are developing formats and guidelines/policies. None of the fifteen states with health as the lead agency reported having an IFSP that meets the requirements of P.L. 99-457. The majority of the states with health as the designated lead agency, thirteen, reported that they are developing formats and guidelines/policies. Three of the states with health as designated lead agency reported that they have no policy in this area but some are developing formats for an IFSP. Of the states with Human Resources designated as the lead agency, two are using an IFSP that meets the requirements of P.L. 99-457. One state with Health and Human Resource designated as lead agency has no policy in this area; the remaining three are developing formats and guidelines/policies. Of the remaining states that have other agencies designated as lead agencies, two are using IFSP's that meet the requirements of P.L. 99-457, one has no policy, and the remaining seven are developing formats and guidelines/policies.

One of the oddities of the survey results is that only one of the seven entitlement states indicated more than modest progress towards the development of IFSP policies. The others apparently are directing their energies elsewhere.

It seems clear from this information that the newness of the requirement for an Individual Family Service Plan has caused many states to be uncertain as to how to approach implementation. There is probably more need for some type of general guidance and

discussion of the many and various issues that are raised by the law in the area of family-professional relationships.

Data Systems

In order to monitor progress toward the development of a comprehensive multidisciplinary statewide system of early intervention services, P.L. 99-457 requires states to report to Congress annually on:

- 1) the numbers of infants and toddlers served,
- 2) the numbers and kinds of services provided,
- 3) the numbers and types of professionals involved in service delivery, and
- 4) the amount of funds expended.

Because states are not required to have the system fully in place until the fourth year of implementation, the requirement to provide the annual report data will be phased in, by stages, over the next two years. For FY88 states are required to report only data on the numbers of infants and toddlers served; beginning in FY89, they must provide the other three types of information.

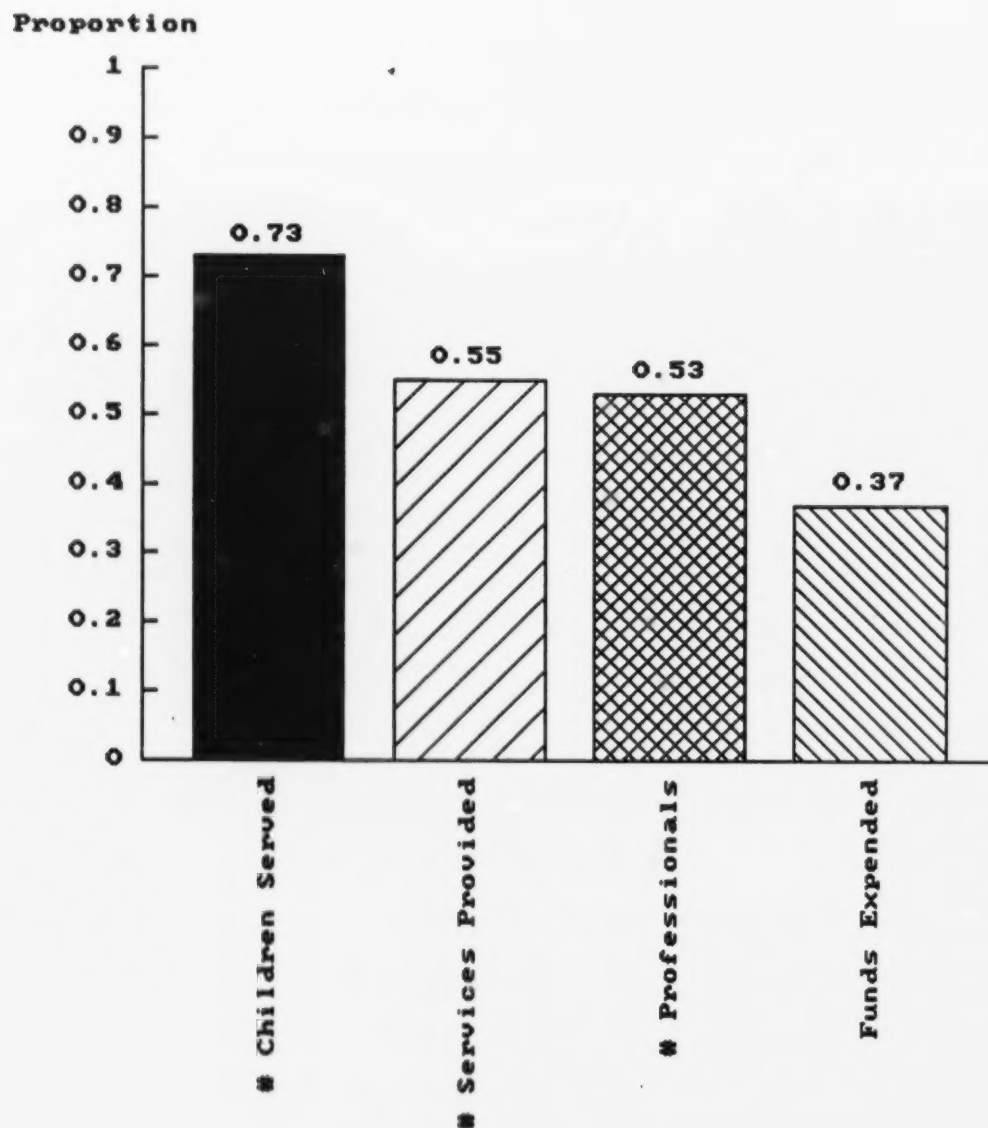
The final item on our survey, asks states to indicate which of the four categories of information required for the annual report are currently available within their state. At the time of the survey, states had not yet received the detailed reporting requirements from the Office of Special Education. Indications of the types of data available, therefore, the answers given here do not necessarily imply that these data will meet these new reporting requirements.

The reader should be aware that states are still developing their data systems, along with the other components of a comprehensive service delivery system. For example, while a state might have information on the children served in some programs or under some agencies, it might not have data from all programs or agencies. Especially in the early stages, it will be difficult to provide wholly unduplicated counts. Still other states are relying on existing data systems, that might combine older preschool children with infants and toddlers.

Of the 50 states and the District of Columbia surveyed, only seven (14%) indicated that there were no data available in any of the four areas required for the annual report. The other 44 indicated that one or more of the categories of data were available. The states have not indicated that their present data meets reporting requirements. Taking each category separately, 37 (73%) states indicated they had data available on the numbers of children served, 28 (55%) on the number of children served by type of service, 27 (53%) on the number of professionals providing service, and 19 (37%) on the amount of funds expended for early intervention services (Figure 7).

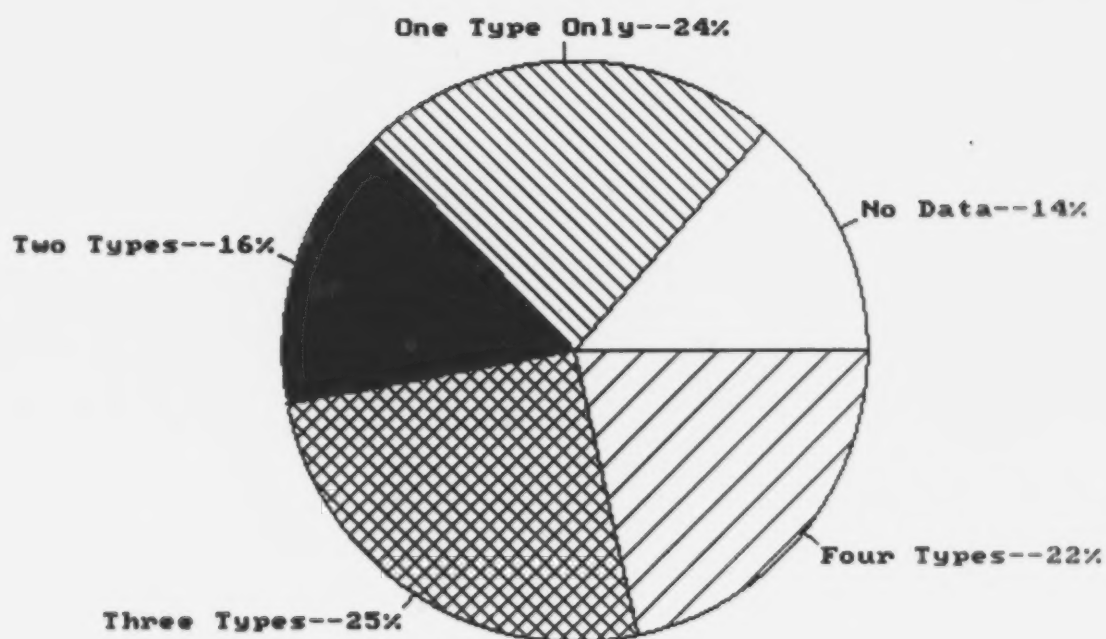
Figure 8 indicates how many states have all categories of annual report data available. Eleven states (22%) indicated they had all four types of data available, and another 13 (25%) indicated data available in three of the types. In the latter group, all had data available on the numbers of handicapped children served, but ten states lacked data on funding. Twenty states reported only one or two types of data: Eight (16%) had

**FIGURE 7. PROPORTION OF STATES REPORTING DATA*
AVAILABLE ON EARLY INTERVENTION SERVICES FOR
INFANTS AND TODDLERS WITH HANDICAPS (n=51)**



*These data might not currently meet reporting requirements of P.L. 99-457. In some instances 0-5 year-olds cannot be disaggregated.

**FIGURE 8. THE NUMBER OF DIFFERENT TYPES OF
DATA AVAILABLE WITHIN A STATE (n=51)**



**Percentage of States Responding
with Each Combination of Data**

two types of data available, and twelve states (24%) had only one.

One could expect that states having entitlements for service for 0-2 year-olds would be more likely to have the kinds of data required. In fact, our expectation is accurate: the median number of types of data available for this group is three, in contrast to a median of two for the non-entitlement states.

There is only one clear relationship between the availability of data and lead agency. The three states with an interagency council designated as lead agency have more types of data available. Those states with health or education lead agencies have roughly similar patterns of available data. However, there is a slight tendency for education lead agencies to have information on the numbers of children served, and for health agencies to have data on personnel and funds expended. Because of the low numbers of states with other agencies designated as lead agencies, it is difficult to identify any clear patterns from them.

The information gathered in the current survey indicate that states have a base and the elements for beginning to build a comprehensive data system but that most of them have a long ways to go.

A Final Word

This initial survey by the Carolina Policy Studies Program has yielded several forms of useful information. First, there is evidence that many states are making a genuine effort to carry out various aspects of this legislation.

It also reveals enormous diversity in the readiness of states to respond to these requirements. The states that already had entitlements appear to be ahead in most of the areas, except for the IFSP, which is a new requirement for everybody.

What will be interesting to observe will be which dimensions of the planning show the most change over the next twelve to eighteen months. There would seem to have been considerable wisdom in giving the states four years to be fully ready to implement comprehensive and coordinated services. Even that length of time may not be sufficient to complete all of the tasks required in this legislation. It is a set of complex tasks that the states have undertaken, and they will need considerable help and assistance to complete their agendas.